KCMS SURVEY RESULTS

Increasing Shared Decision-Making in Hemophilia Care

King County Medical Society
COMMUNITY FOUNDATION

Funded by an independent grant from Pfizer and Genmab
An Educational Module for Healthcare Professionals

Pfizer

Genmab

SECTION 1

Introduction & Survey Insights

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Research funded **Pfizer** and **Genmab**

Project Overview

- The King County Medical Society (KCMS) has been a trusted leader in healthcare advocacy and education for over a century. It represents thousands of healthcare professionals across Washington State.
- As part of our commitment to improving patient outcomes, we launched a survey-driven initiative to identify key challenges in hemophilia care and shared decision-making (SDM).
- Rapid advancements in hemophilia treatment make it difficult for healthcare professionals to stay informed about emerging therapies and best practices. Our survey highlighted critical knowledge, confidence, and SDM gaps. Many healthcare professionals reported a lack of confidence in discussing treatment options, with key barriers including time constraints, limited resources, and patient comprehension issues.
- This presentation provides an overview of our survey findings, which will help shape KCMS-created educational materials and decision-making tools.
- This initiative aims to equip healthcare professionals and patients with the latest knowledge on emerging therapies, ensuring informed, personalized treatment choices.

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Learning Objectives

In collaboration with key stakeholders, King County Medical Society (KCMS) will develop educational modules based on the results of the baseline survey that will equip healthcare professionals with the knowledge and tools to:

Understand Key Advancements

Gain an overview of emerging hemophilia therapies, including gene therapy, rebalancing agents, and non-factor treatments.

Identify Shared Decision-Making (SDM) Barriers

Recognize common challenges healthcare professionals face when discussing treatment options with patients.

Explore Practical Solutions

Review decision aids and communication strategies to improve patient discussions.

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How We Conduct This Research

To ensure broad participation, we advertised our baseline survey for six weeks across multiple channels to encourage broad healthcare professional engagement:

- All major social media platforms (LinkedIn, Twitter, Facebook, and Instagram)
- KCMS's monthly newsletter, reaching over 7,000 healthcare professionals
- Direct outreach to physicians, hematologists, and patient advocacy groups

We aimed to gain insights from frontline healthcare professionals and uncover key barriers in discussing and implementing emerging hemophilia treatments in clinical settings.

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Key Findings from the Survey

We were grateful for the participation of healthcare professionals, including physicians, PAs, nurses, and support staff. Based on survey results, they shared that:

- 57% of healthcare professionals rated their knowledge of emerging hemophilia therapies as low or very low.
- Many reported a lack of confidence in sharing decision-making discussions with patients.
- The most significant barriers to SDM included time constraints (35%), insufficient training/resources (49%), and patient comprehension challenges (30%).
- The most requested educational topics were gene therapy, rebalancing agents, and non-factor therapies.

This initiative, funded by Pfizer and Genmab, will directly respond to these findings. Through educational materials, decision aids, and social media outreach, we aim to empower healthcare professionals with the tools to improve patient care and shared decision-making in hemophilia treatment.

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SECTION 2

Understanding Hemophilia & Treatment Options

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What is Hemophilia?

Definition

Hemophilia is a rare genetic bleeding disorder in which the blood does not clot properly due to the absence or dysfunction of clotting factors.

Types of hemophilia

Hemophilia A (more common):
Deficiency of Factor VIII

Hemophilia B:
Deficiency of Factor IX

Hemophilia C (rare):
Deficiency of Factor XI

Incidence: Hemophilia A affects 1 in 5,000 male births, while Hemophilia B is rarer, occurring in 1 in 25,000 male births.

Cause: X-linked recessive inheritance; predominantly affects males, while females are typically carriers.

Symptoms: Excessive bleeding, spontaneous joint and muscle bleeding, prolonged bleeding after injuries or surgery.

Severity Levels

- **Mild** (5-40% clotting factor levels)
  Bleeding occurs after significant injury.
- **Moderate** (1-5%)
  Bleeding after minor trauma, occasional spontaneous bleeds.
- **Severe** (<1%)
  Frequent spontaneous bleeding episodes, particularly in joints and muscles.

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Levels of Severity Hemophilia

Mild

5-40% clotting factor levels

- Likely to bruise easily and have prolonged bleeding after minor cuts.
- May have bleeding problems after having teeth taken out, surgery, medical procedures that cut the skin or a bad injury or accident.
- Females may have heavy menstrual bleeding (heavy periods).
- Females may have bleeding problems with childbirth.
- Might only have bleeding problems requiring medical attention very occasionally.

Moderate

1-5% clotting factor levels

- Likely to bruise easily and have prolonged bleeding after minor cuts.
- May have bleeding problems after minor injuries, such as sporting injuries.
- Can have bleeding problems after surgery, medical or dental procedures that cut the skin or a bad injury.
- Females likely to have heavy periods.
- Females sometimes have bleeding problems with childbirth.
- Occasionally have a bleed for no obvious reason.

Severe

<1% clotting factor levels

- Likely to bruise easily and have prolonged bleeding after minor cuts.
- Often have bleeds into joints, muscles and soft tissues.
- Can have bleeds for no obvious reason ('spontaneous bleeds'), as well as after surgery, medical or dental procedures that cut the skin and injuries including minor bumps or knocks.
- Females likely to have heavy periods.
- Females likely to have bleeding problems with childbirth.

www.haemophilia.org.au/HFA/media/Documents/Haemophilia/Haemophilia-booklet.pdf

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Pathophysiology of Hemophilia

The Normal Clotting Process

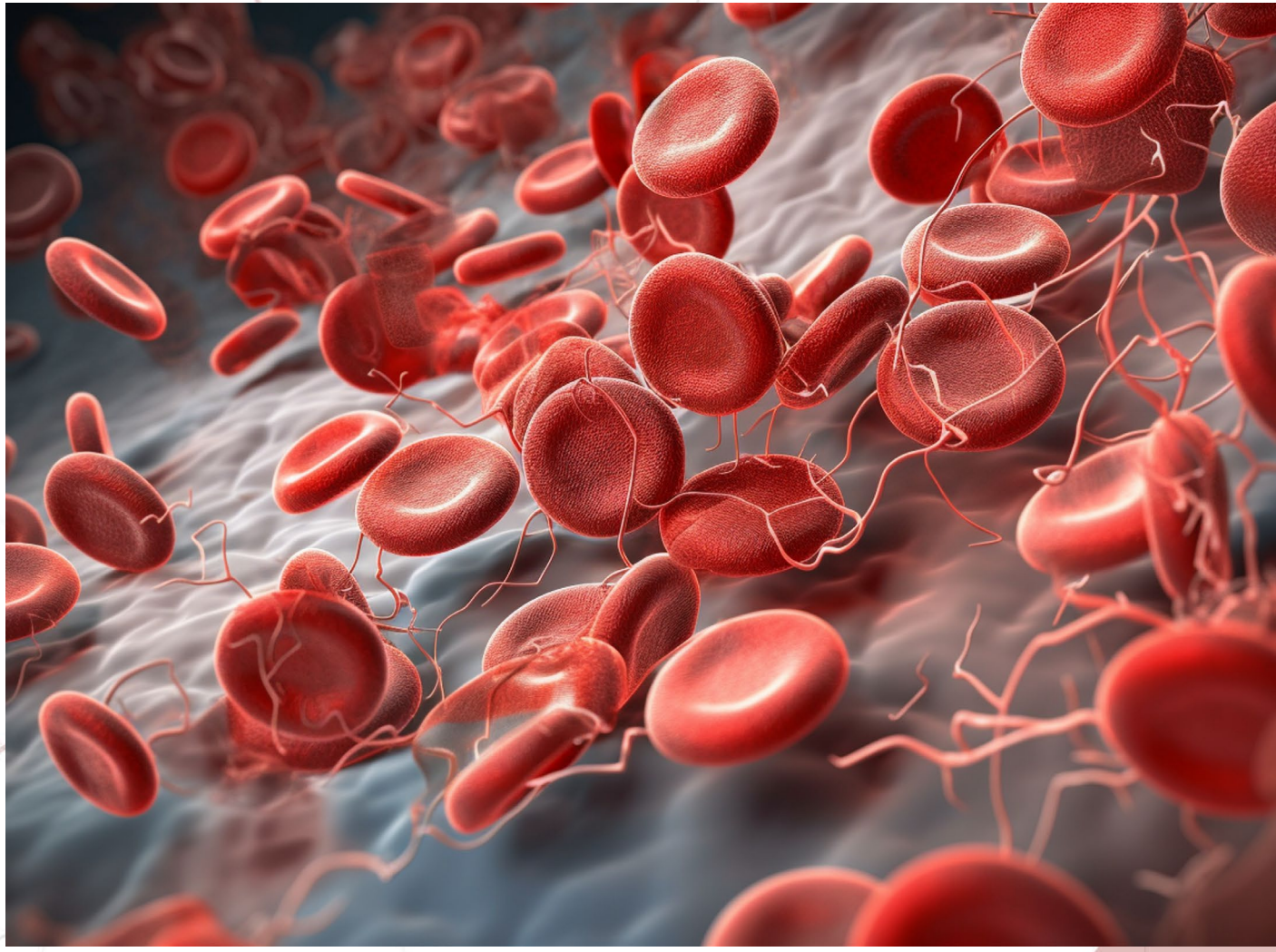
The coagulation cascade involves a series of enzymatic reactions that activate clotting factors, forming a stable clot.

How Hemophilia Disrupts Clotting

Without Factor VIII or IX, the cascade is interrupted, preventing fibrin clot formation and leading to prolonged bleeding episodes.

Impact on Joint Health

Recurrent joint bleeds (hemarthrosis) lead to chronic pain, inflammation, and long-term joint damage.



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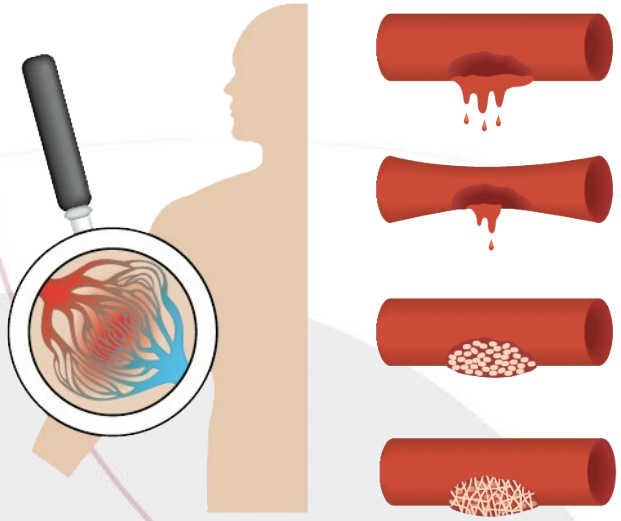
Hemophilia and Clotting Process

How bleeding starts and stops

Normal clotting process



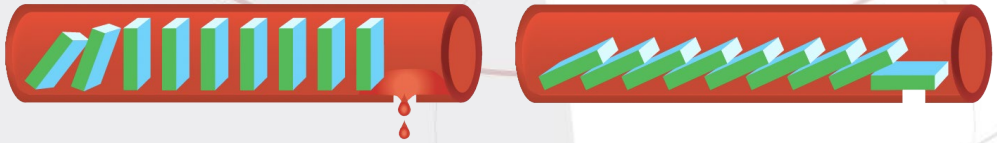
The **capillary** is injured and blood leaks out.

The capillary tightens up to slow bleeding.

Then blood cells called **platelets** make a plug to patch the hole.

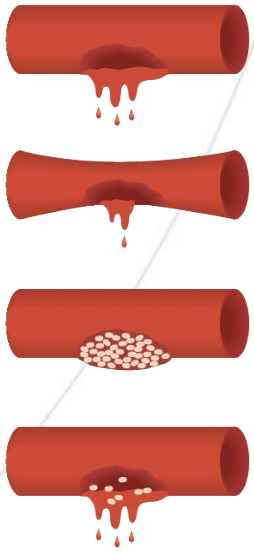
Next, many clotting factors in plasma knit together to make a clot over the plug. This makes the plug stronger and stops bleeding.

Clotting factors at work to stop bleeding



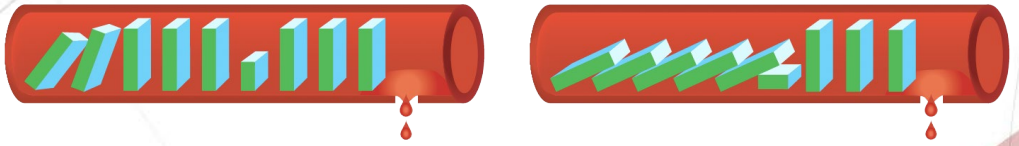
www.wecapable.com/hemophilia-types-definition-genetics-treatment-disability/

Clotting in hemophilia



In hemophilia there is not enough factor for the clot to stay together, so bleeding continues for longer than usual, but not faster.

Clotting factors in hemophilia



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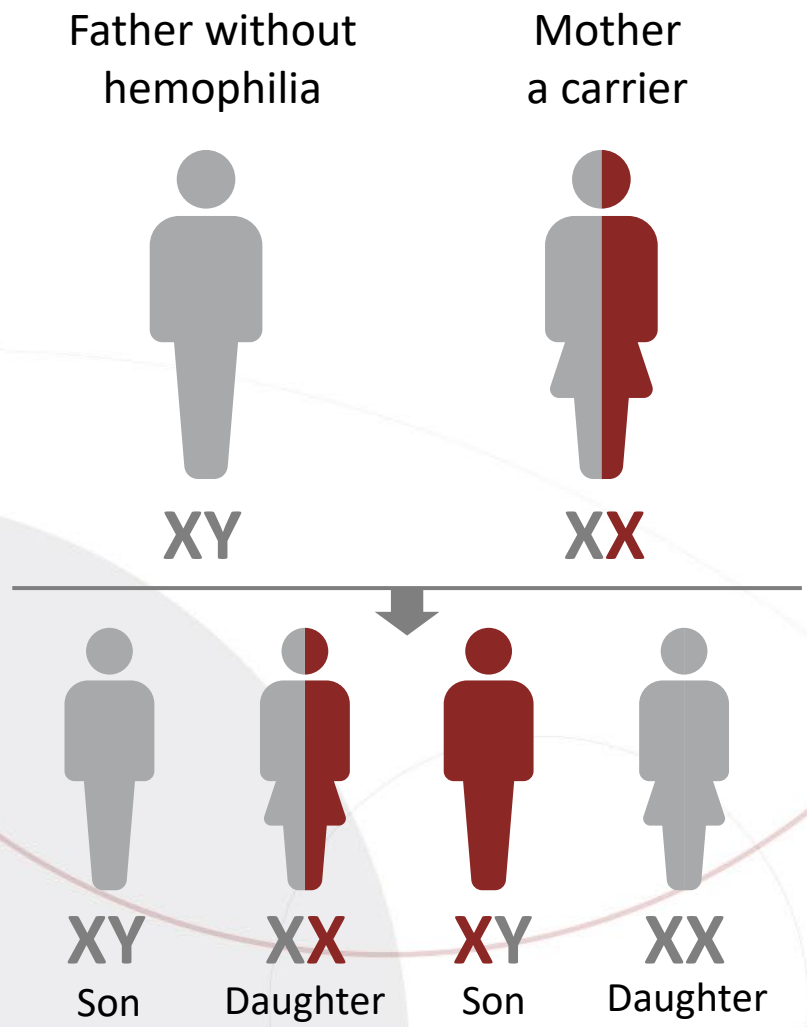
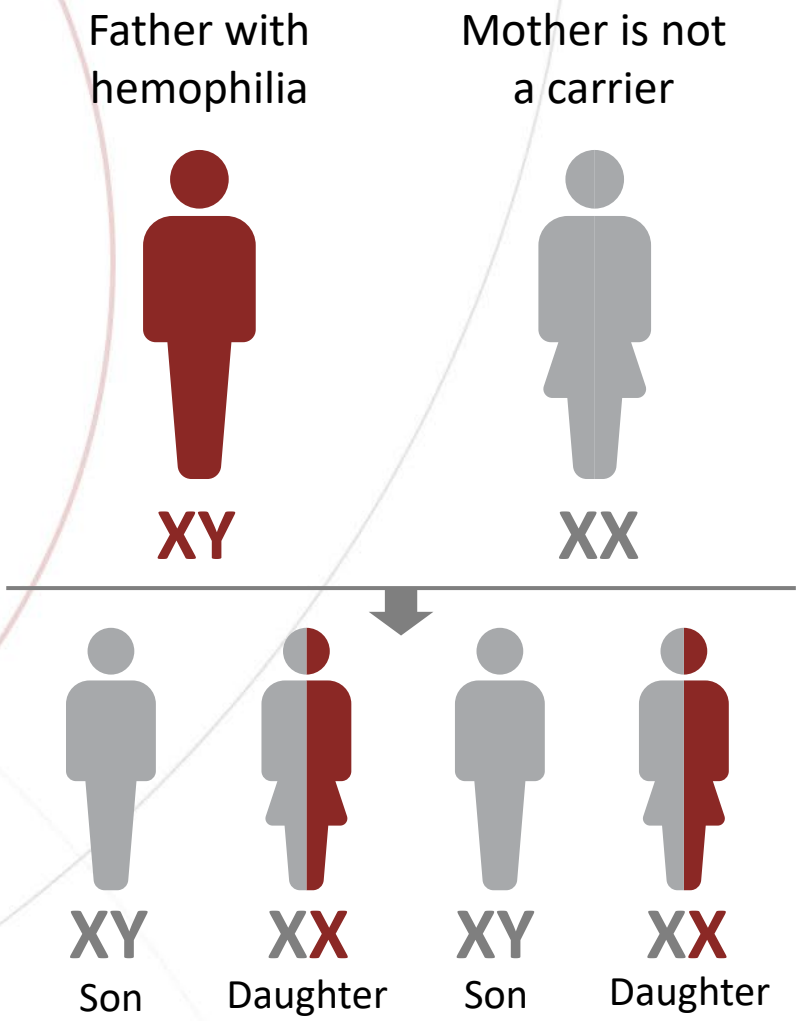
The Genetics of Hemophilia





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THANK YOU

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